

# Ehlers-Danlos Syndrome

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UNDERSTANDING HOW TO  
SUSPEND OUR STRETCHY  
FRIENDS

# Disclaimer

Taking this Class  
does **NOT**

- Mean you have been trained by us
  - Mean you are ready to offer all services to clients with EDS
  - Mean you are done learning!
- The views expressed in this presentation are those of a professional piercer and someone with EDS , they may not reflect the views of OSC
  - The intention of this presentation is to educate other piercers and facilitators
  - Everything is correct to the best of our knowledge- but medicine is always evolving! Some of this may change as we learn more
  - Anon suggestions/feedback can be left at [lynnloheide.com/EDSclass](http://lynnloheide.com/EDSclass)

## MEET LYNN

- They/Them
- Piercing for 14 years
- Founder Nexus Body Arts
- APP Member for 7 years
- Professional Educator
- Experienced piercing clients with EDS
- Experienced in facilitating suspensions for folks with EDS



@LynnLoheide



## MEET BRIEN

- He/Him
- Has EDS
- Suspension Facilitator of 21 years
- Professional Glassblower
- Experienced in facilitating suspensions for folks with EDS
- Hates Public Speaking (like a lot)



@Brien9Fingers



## MEET MAHS

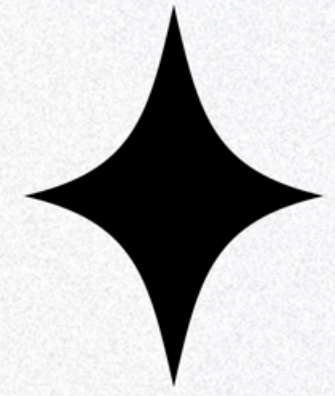
- They/She
- 32
- Has EDS
- Diagnosed as an adult
- Suspending for 6ish years
- Works Counter at Absolutiuon
- Has the 2 cutest cats you've ever met



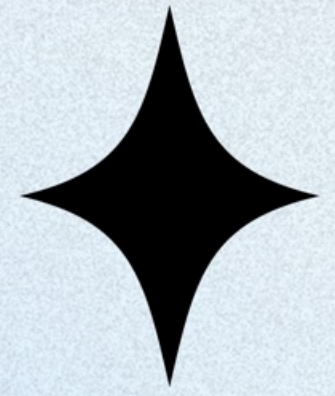
# ✦ **What IS EDS?** ✦

Ehlers–Danlos syndrome is a group of inherited disorders that affect your connective tissues — primarily your skin, joints and blood vessel walls. Connective tissue is a complex mixture of proteins and other substances that provide strength and elasticity to the underlying structures in your body.

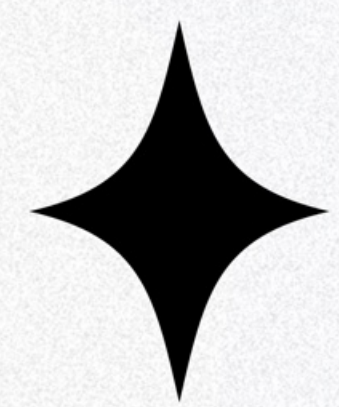
- **Classical EDS:** Characterized by joint hypermobility, stretchy and fragile skin, and easy bruising.
- **Hypermobile EDS:** The most common type, with joint hypermobility, skin hyperextensibility, and a tendency to develop chronic pain and dislocations.
- **Vascular EDS:** A rare and life-threatening type, characterized by fragile blood vessels that can rupture spontaneously.
- **Kyphoscoliotic EDS:** Severe spinal curvature, joint stiffness, and muscle weakness.
- **Arthrochalasia EDS:** Extreme joint hypermobility, leading to frequent dislocations and joint instability.
- **Dermatosparaxis EDS:** Extremely fragile skin that tears easily and heals poorly.
- **Brittle Cornea Syndrome:** Thin and fragile corneas that are prone to rupture.
- **Spondylodysplastic EDS:** Short stature, joint stiffness, and skeletal abnormalities.
- **Musculocontractural EDS:** Muscle weakness, joint stiffness, and developmental delays.
- **Periodontal EDS:** Severe gum disease and tooth loss.
- **Cardiac-Valvular EDS:** Heart valve defects and other cardiovascular problems.
- **Myopathic EDS:** Muscle weakness and hypotonia.
- **X-linked EDS:** A rare form with unique features, including joint hypermobility and skin changes



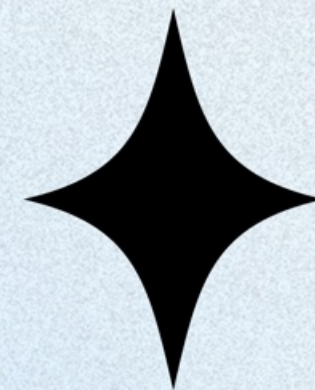
# **EDS has 'Friends'**



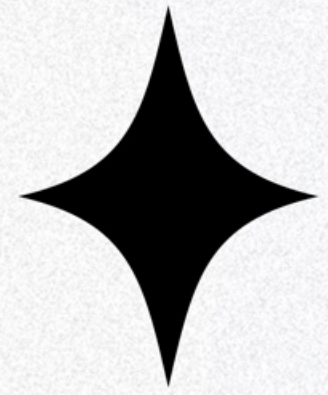
Some conditions are co-travelers with EDS. This includes Disautonomia (a disruption in the autonomic nervous system) & POTS, Mast Cell Activation (inappropriate activation of immune cells), Gastrointestinal concerns, and Autoimmune issues.



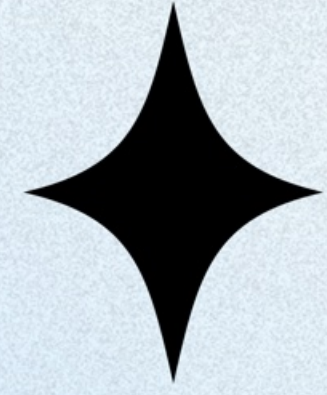
# **Different People** **Different Presentation**



While knowing generally the different types of EDS is helpful, it can present differently in different bodies. Know the basics, and then talk to each person about their unique situation!



# Diagnosis



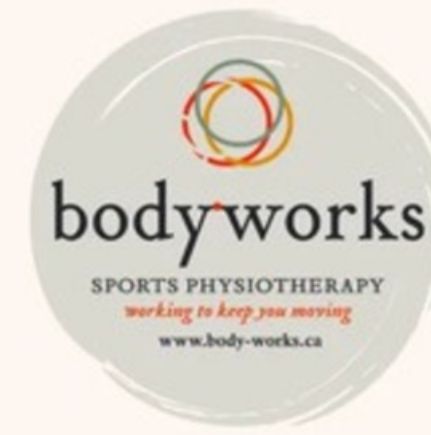
Diagnosis for EDS can be rare, due to expensive testing, limited health care options, and a propensity to overlook EDS in diagnosis. Women represent 70-89% of diagnosed cases.

If you see signs of EDS, proceed with caution to be safe. Believe clients who bring up symptoms, even without an official diagnosis.

"When you hear hoofbeats, think horses, not *zebras*"



# Ehlers-Danlos Syndrome (EDS)



Joint  
Hypermobility

Tissue Fragility



Joint  
Instability



Headaches



Poor Wound  
Healing



Acute &  
Chronic Pain



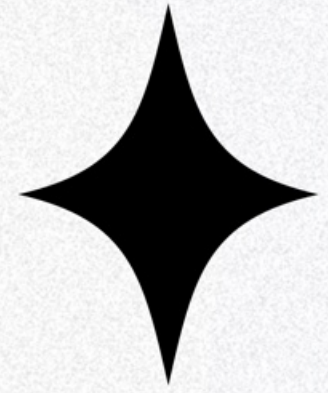
# Skin

## Hyperextensibility

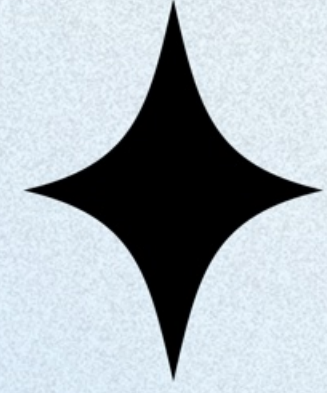
This is an excessive elasticity or stretchiness of the skin, while normal skin presents with a moderate level of elasticity. Skin may appear thin, translucent, or velvety. Prone to easy bruising and scarring.



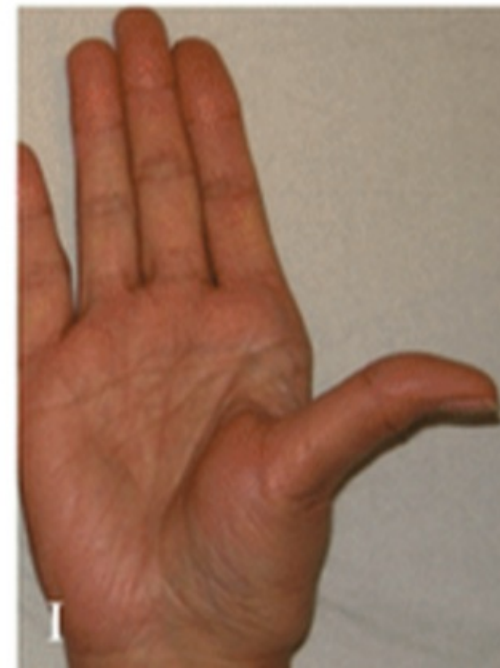
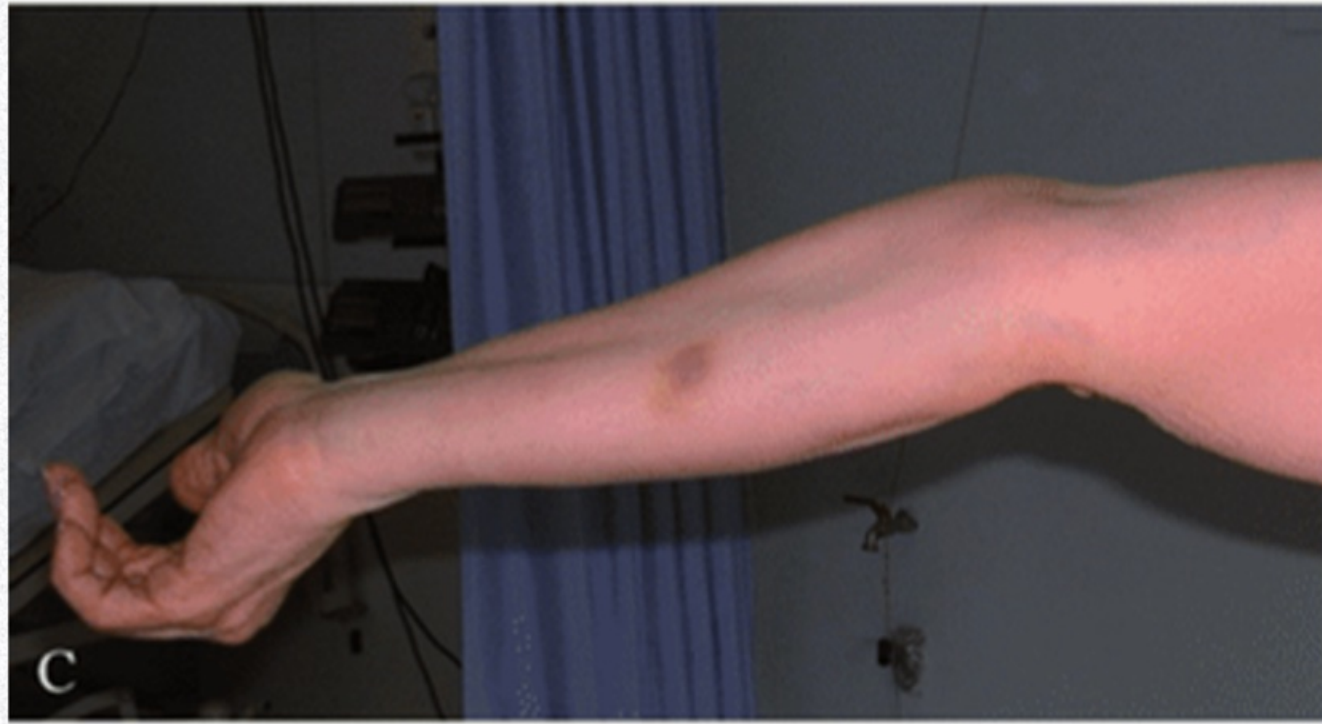




# Hypermobility



Signs of hypermobility include hypermobile joints, which can move beyond the normal range of motion and may lead to dislocations. Other common signs are chronic widespread pain, increased fatigue and poor stamina, and frequent, unexplained injuries like sprains and dislocations.



# ✦ **Joint Dislocation** ✦

Joint dislocation is common in EDS due to inherently weak connective tissues (such as collagen) that fail to properly support joints, also leading to hypermobility and instability.

# ✦ **Tissue Fragility** ✦

Tissue fragility in EDS refers to the inherent weakness of connective tissue, primarily collagen, leading to increased susceptibility to injury, such as easy bruising, delayed wound healing, and atrophic scars.

This fragility can affect various body systems, including the skin, blood vessels, and internal organs, manifesting in symptoms like skin splitting, hernias, or even organ rupture

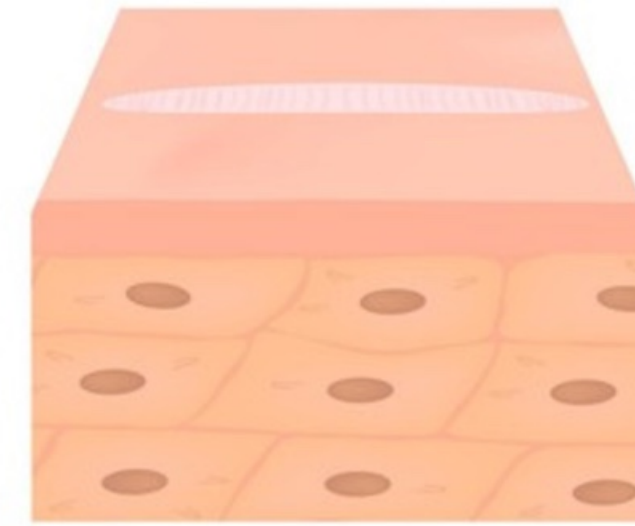
# ✦ **Atrophic Scarring** ✦

EDS affects the body's ability to produce and organize collagen, leading to weak and fragile wounds that are prone to scarring.

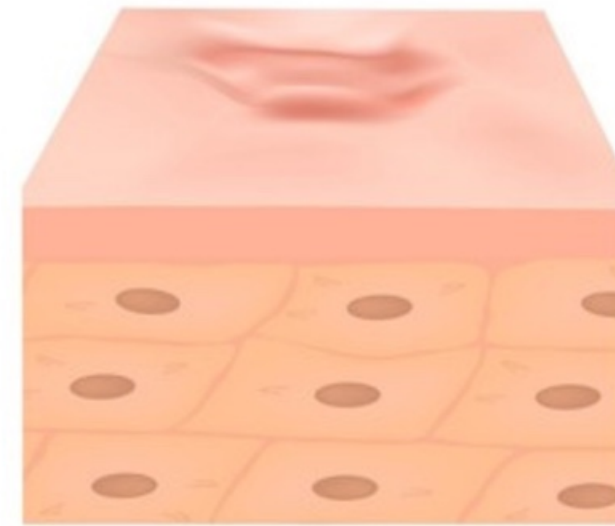
Certain types of EDS are classified with abnormal elastic fibers, which also contribute to scar tissue formation. "Cigarette paper" scars are somewhat common.



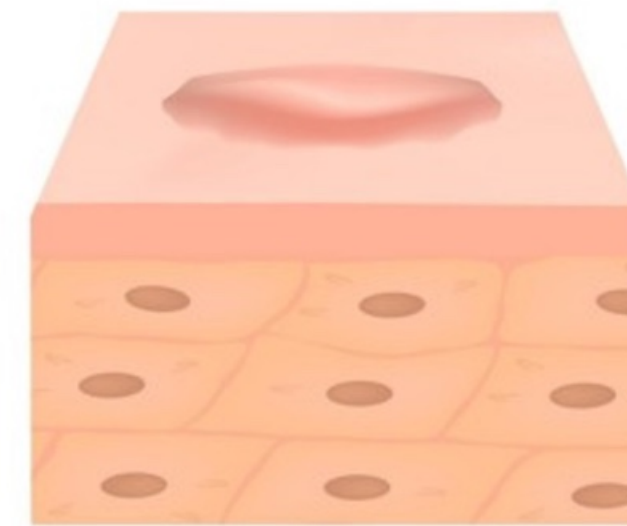
# Types of Scars



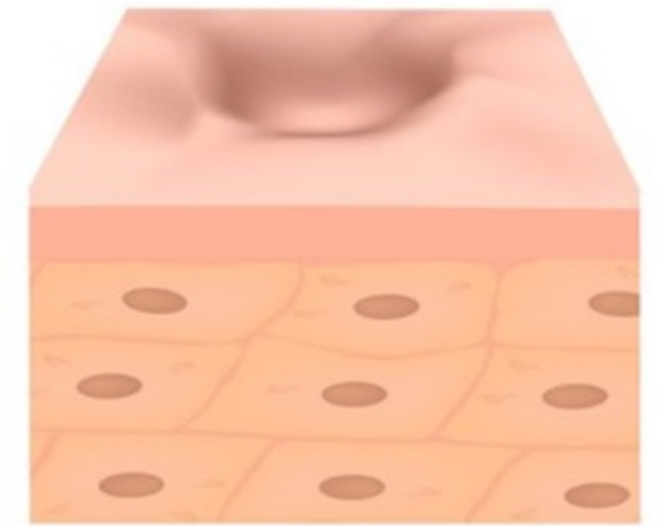
Normotrophic Scar



Hypertrophic Scar

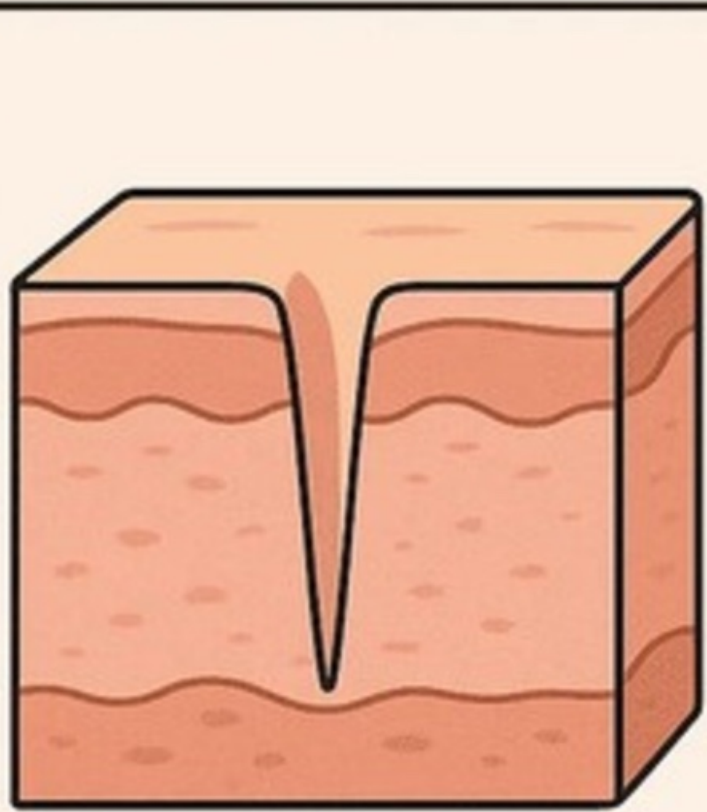


Keloid Scar

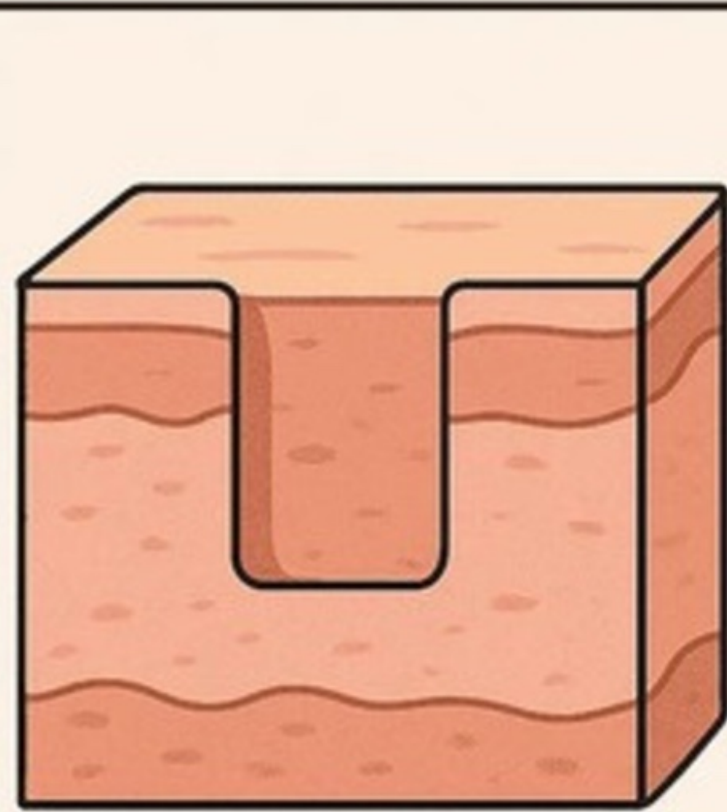


Atrophic Scar

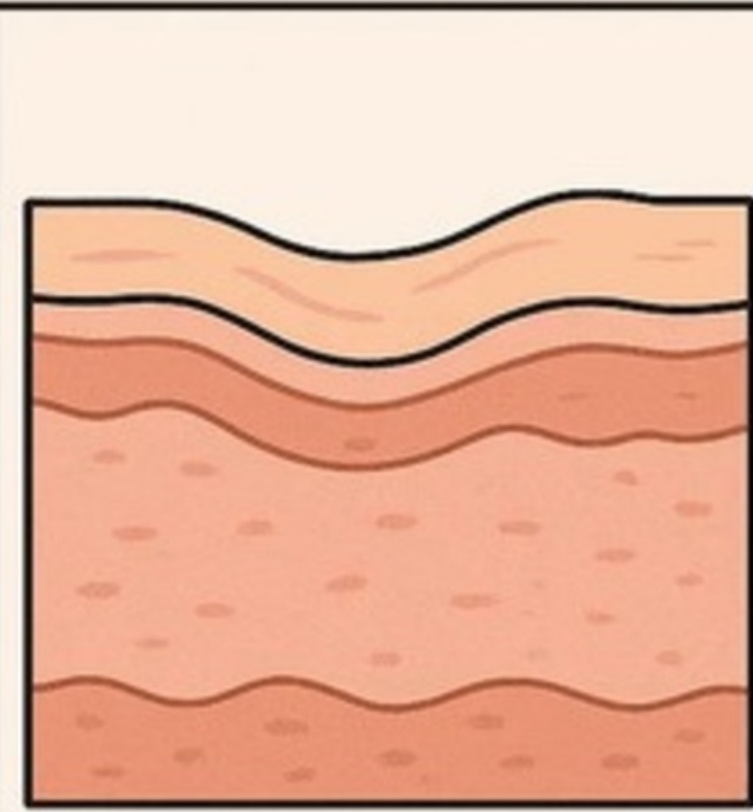
# ATROPHIC SCAR TYPES



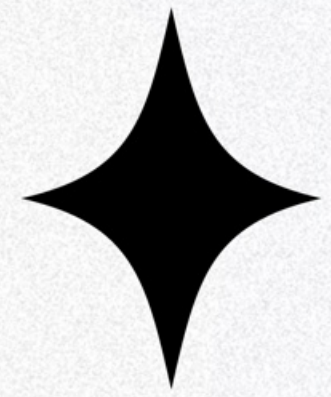
**Ice Pick Scars**



**Boxcar Scars**



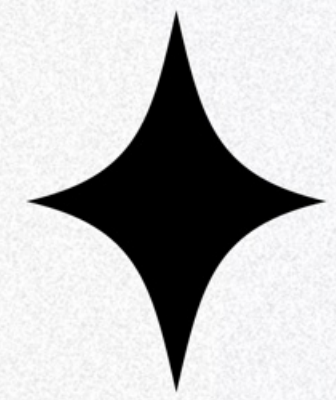
**Rolling Scars**



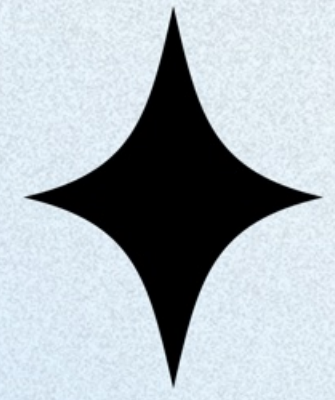
# Delayed Healing



Collagen is essential to wound healing. EDS causes collagen defects, which lead to delayed wound healing. Wounds can frequently reopen or heal poorly. Specific dressings, avoiding wound tension, and anticipating increased potential for hematoma or dehiscence, is essential. Expect prolonged healing processes.



# **Poor Proprioception**



Proprioception is the sense of body position and movement, allowing us to coordinate our actions and maintain our balance. Poor proprioception occurs when this sense is impaired, leading to difficulties with motor control and coordination

# ✦ **Non-Restorative Sleep** ✦

People with EDS are prone to non-restorative sleep due to connective tissue and joint issues. This can cause delayed healing, fatigue, brain fog, memory loss, and leave those with EDS more prone to injury and illness.



## HIGHLIGHTS

- 1 Clients with EDS have fragile skin and cartilage, that won't respond to being pierced the way non-EDS skin does.
- 2 EDS can cause prolonged, difficult wound healing, and more fragile scars
- 3 Clients with EDS often have severe chronic pain, fatigue, headaches, and other symptoms that affect their daily life



## **BODY SUSPENSION WITH EDS**

- What to Consider
- Suspendee Communication
- Hook Placement
- Joint Support
- Piercing Techniques
- Tear Considerations & Suturing
- Fainting and POTS
- Wound Care
- Suspendee Followup



## MAIN CONSIDERATIONS

1 Tears

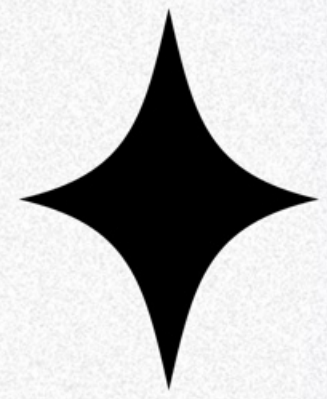
2 Joint Dislocation  
or Stress

3 Healing Concerns

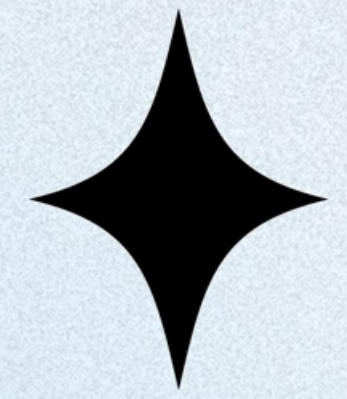
# ✦ **Different People** ✦ **Different Presentation**

There are many different types of EDS, and they can present differently in each person.

Talk to your suspendee! Ask how EDS presents for them. Discuss what concerns they may have, and what accommodations they may need

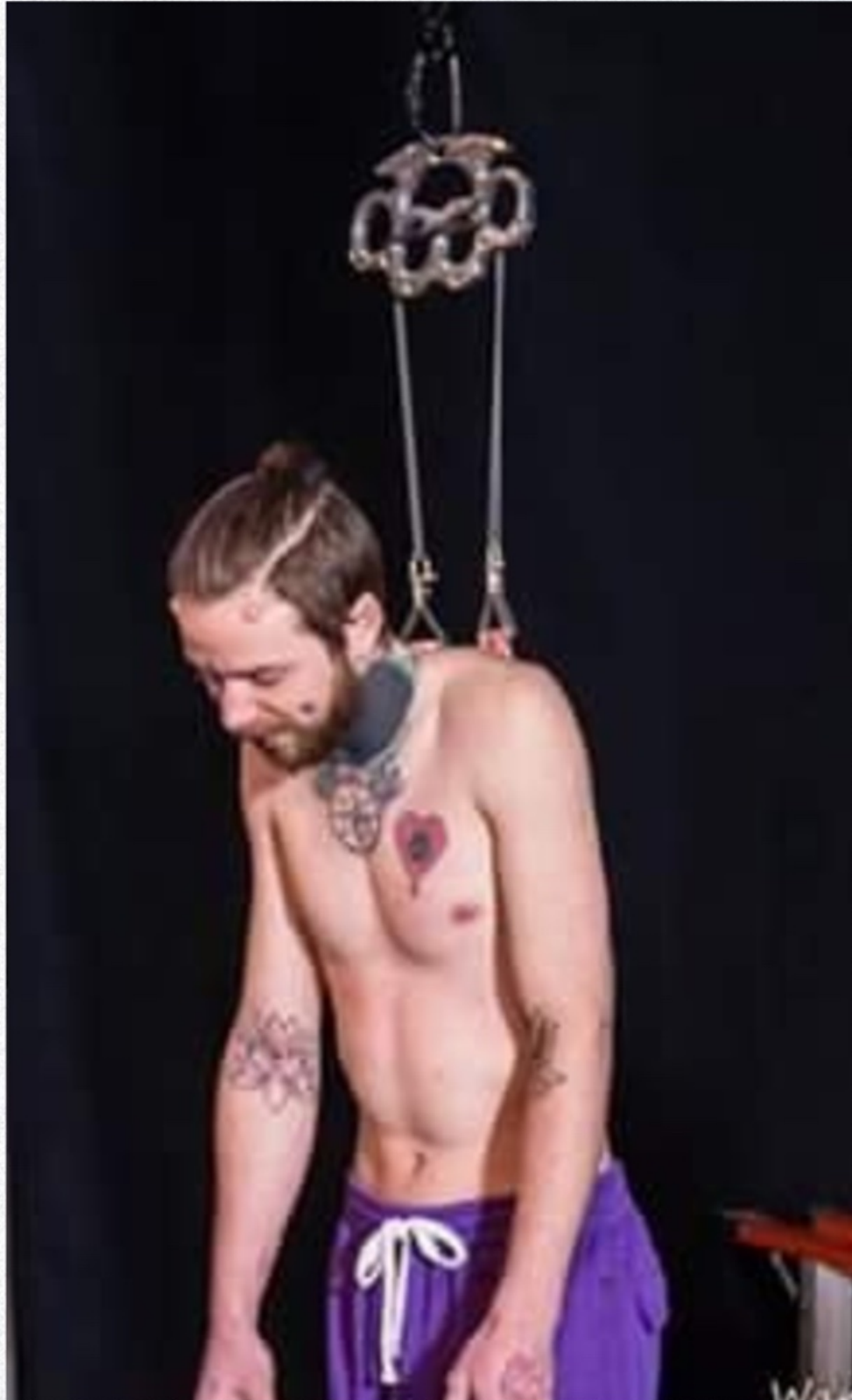


# Hook Placement



Raise your hand if you feel comfortable placing hooks for a 2pt back suspension

# Hook Placement



- Pierce for where the skin will end up and where the body will end up
- Consider tension on muscles, joints, and organs
- It's very easy to pierce too deep/shallow







# Joint Support



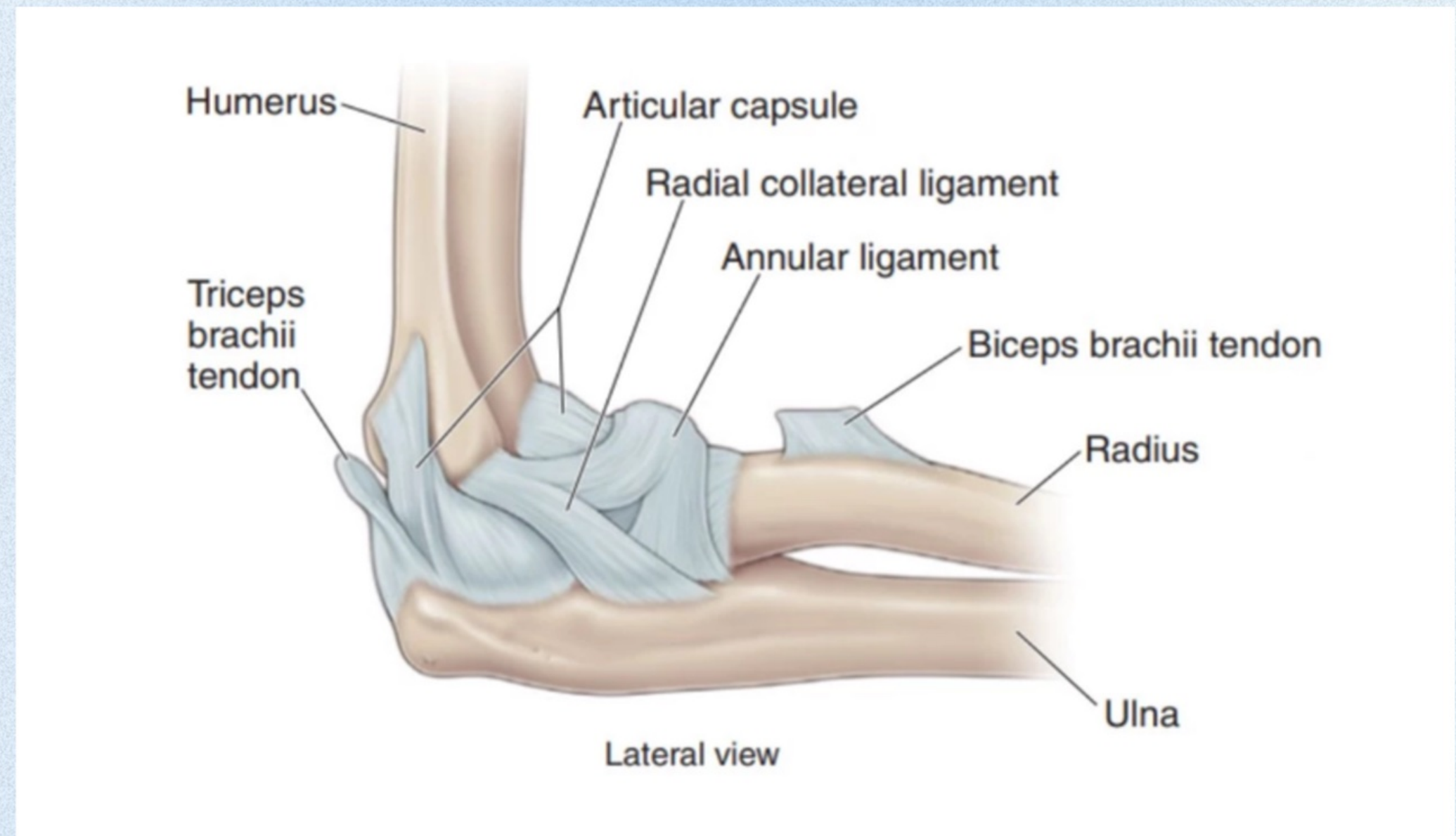
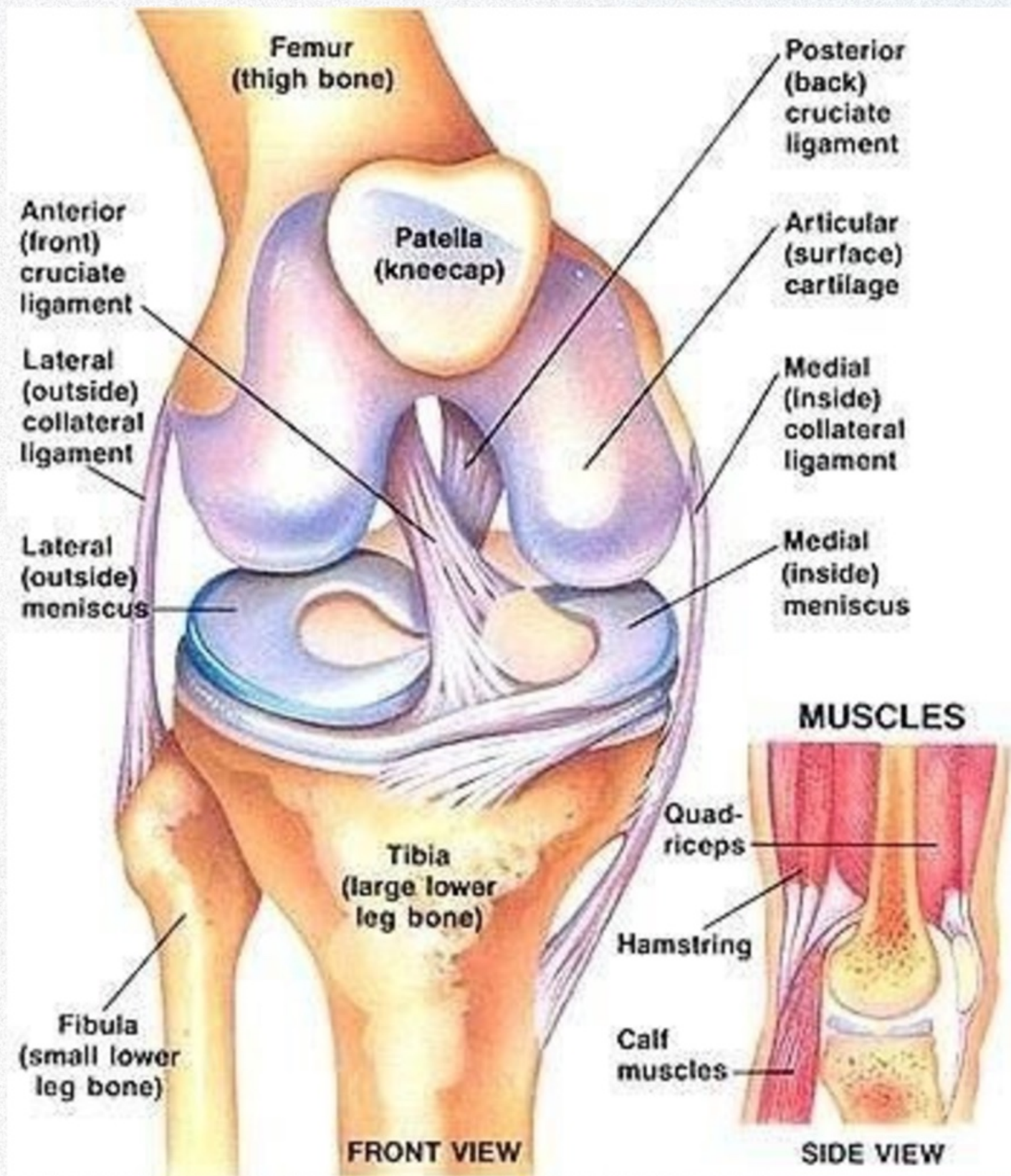
- Consider the stress put on joints in different positions
- Just because they can stretch that far doesn't mean you should rig it stretched that far
- Accessible options for getting off the ground
  - Be able to attach support rigging if needed



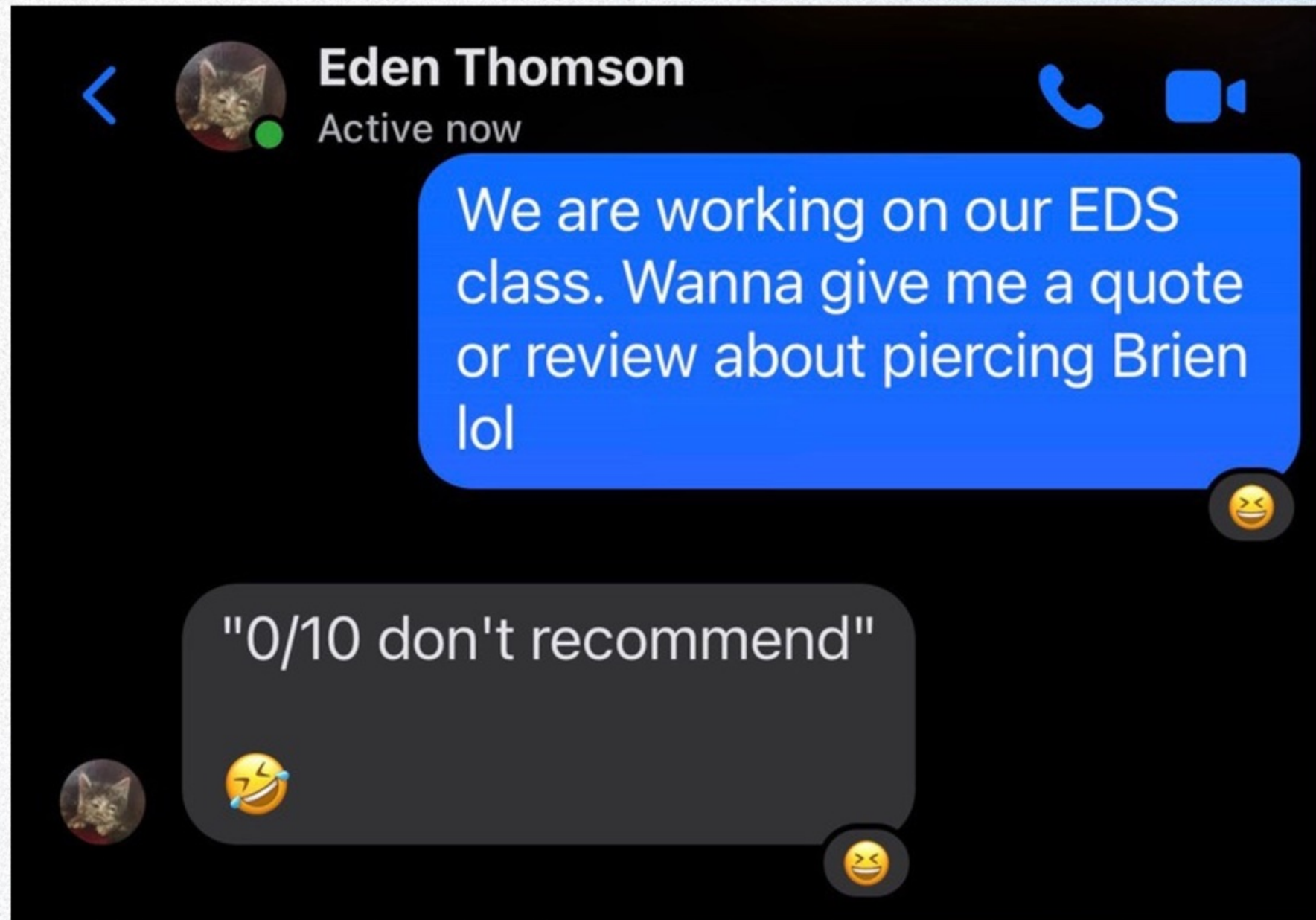
“ I’ve done knee hooks twice, and as the skin takes more and more weight, I can feel the unnatural pulling of my kneecaps. It’s nauseating, and really scary. My knee dislocations are the most painful, as they tend to dislocate ‘inwards’ and lock the leg in place. My brain can’t stay on as that tension builds. It’s *just fucked.*”

# Ligament Tears

Small ligaments and tendons are at a much greater risk of permanent damage in people with connective tissue disorders



# Piercing Techniques

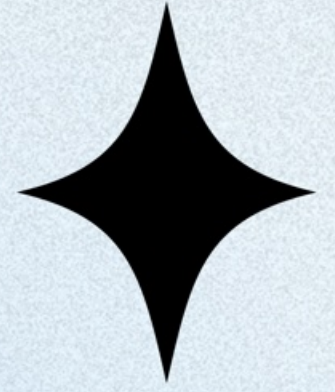
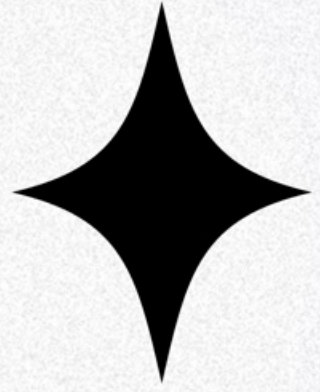


- Don't be afraid to ask for an extra hand
- **Brace**
- Precision is more important than speed
- Use Good Needles!

# Tears and Sutures

- Always monitor for tears (never “assume” hooks are fine)
- May be harder to bring skin to meet when suturing, skin may pucker or roll
- It’s easy to suture too deep
- Care should be taken to consider scarring

# Fainting



- POTS is a large comorbidity with EDS
- Fainting can occur at any time
- Discuss suspendee's preference before starting
- Know what signs to watch for
- Have glucose handy

# “Bye Bitch”

“I never really know how bad it’s going to be as I go into it, but it absolutely depends on the day. You know how sometimes you do a suspension, and it goes surprisingly easy and smoothly? But then you do the exact same one, and it’s awful and shit and you call it early? It feels a bit like that. There is almost always an element of it, however.”

Out of 15 suspensions, Mahs has only remained fully conscious for 2



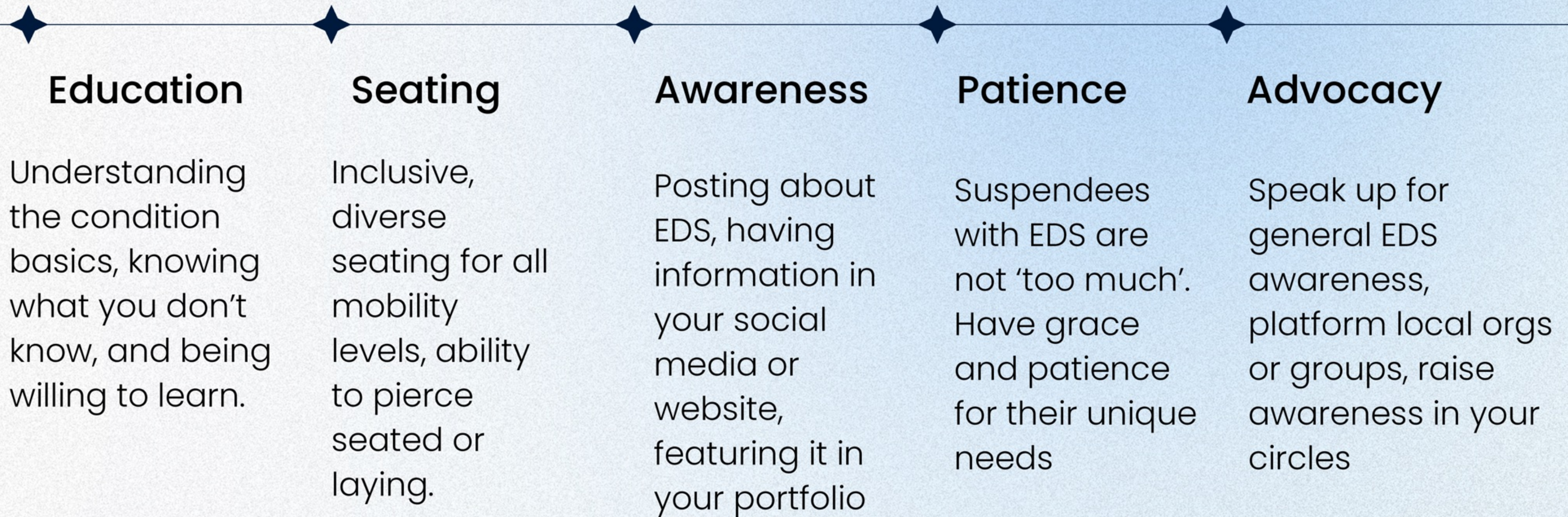


# Wound Care & Followups



- Check in more frequently for suspendees with EDS, and over a longer period of time
- If consented to, collect data on scarring for your reference, and so suspendee can learn their bodies needs
- Encourage suspendees to do scar care

# CREATING EDS SAFE SPACES





# Patience



“Admittedly, I didn't think much of it. My experience was all I knew, and our other regular suspenders are.. really good suspenders, if that makes sense. I just thought I was shit and being dramatic. I also had some pretty gross thoughts that perhaps I was attention-seeking, which I've been accused of in the past through injury.

It wasn't until you turned up and talked about it, I started looking into it. Knowledge is power, and through knowing what makes it worse, makes it easier.”



# Patience



When asked, the majority of suspendees we facilitate for with EDS have mentioned feeling like they are “bad” at suspending.

Most have had at least one experience where their needs were not fully met.

## SOURCES

**Disjointed:** Navigating the Diagnosis and Management of Hypermobile Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorders by Anne Maitland

<https://www.ehlers-danlos.com>

**Sobey G. Ehlers-Danlos syndrome - a commonly misunderstood group of conditions.** Clin Med (Lond). 2014 Aug;14(4):432-6. doi: 10.7861/clinmedicine.14-4-432. PMID: 25099849; PMCID: PMC4952841.



## SOURCES

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**DePaepe A, Malfait F. The Ehlers–Danlos syndrome, a disorder with many faces.**

Clin Genet 2012;82:1–11. 10.1111/j.1399–0004.2012.01858.x





Thank You!